*autism*

# Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults

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## Abstract

Previous research shows that autistic people have high levels of co-occurring mental health conditions. Yet, a number of case reports have revealed that mental health conditions are often misdiagnosed in autistic individuals. A total of 420 adults who identified as autistic, possibly autistic or non-autistic completed an online survey consisting of questions regarding mental health diagnoses they received, whether they agreed with those diagnoses and if not why. Autistic and possibly autistic participants were more likely to report receiving mental health diagnoses compared to non-autistic participants, but were less likely to agree with those diagnoses. Thematic analysis revealed the participants' main reasons for disagreement were that (1) they felt their autism characteristics were being confused with mental health conditions by healthcare professionals and (2) they perceived their own mental health difficulties to be resultant of ASC. Participants attributed these to the clinical barriers they experienced, including healthcare professionals' lack of autism awareness and lack of communication, which in turn prevented them from receiving appropriate support. This study highlights the need for autism awareness training for healthcare professionals and the need to develop tools and interventions to accurately diagnose and effectively treat mental health conditions in autistic individuals.

## Introduction

Autism spectrum condition (ASC)[1] is classified as a neurodevelopmental condition, characterised by persistent difficulties in social communication and interaction, as well as restricted, repetitive patterns of behaviour, interests and activities (American Psychiatric Association (APA), 2013). These symptoms present during early development and cause a range of strengths and difficulties in multiple domains. Recent studies suggest that autistic difficulties could increase the likelihood of being exposed to risk factors for developing mental health conditions. For example, higher autistic traits were associated with self-reported loneliness in autistic adults (Hedley et al., 2018) and the experience of social disconnectedness, and feeling a burden on others in the general population (Pelton and Cassidy, 2017); these factors in turn increased the risk of both depression and suicidality. Indeed, Lever and Geurts (2016) established that 79% of autistic adults met the criteria for some form of psychiatric co-occurring condition

during their lifetime, with mood and anxiety disorders being the most common, and at a significantly greater rate compared to non-autistic adults.

Despite increased risk factors for, and incidence of, mental health conditions in autistic individuals, conditions such as depression may still be under-diagnosed given the lack of validated assessment tools able to accurately detect the unique presentation of mental health difficulties in this group (Cassidy et al., 2018a, 2018b). Although ASC is not

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a mental health condition, the characteristics of ASC can overlap with many indicators of mental health conditions; for example, social withdrawal, appetite and sleep disturbance are common characteristics in both ASC and depression (Stewart et al., 2006). This means that an established diagnosis of ASC could overshadow the presence of mental health symptoms, potentially leaving co-occurring mental health conditions unrecognised (Matson and Williams, 2013). The consequences of failing to accurately diagnose co-occurring mental health conditions are potentially devastating and increase the risk of contemplating, planning (Cassidy et al., 2014) and dying by suicide (Hirvikoski et al., 2016).

It is also possible that symptom overlap could lead to overdiagnosis and misdiagnosis of mental health conditions in autistic individuals (Lai and Baron-Cohen, 2015). In a case series, Dosseter (2007) re-evaluated four young clients, aged 8–16 years, who had been originally diagnosed with early-onset psychosis. The individuals reported unusual experiences, exhibited bizarre behaviours and had preoccupations with objects and imaginary people or worlds. However, when the clients' impairments in social communication and reciprocity were taken into consideration, it was concluded that clients' presentation could be better explained by ASC, with the preoccupations accounted for under 'restricted, repetitive patterns of behaviour, interest, and activities' (APA, 2013). Other case reports (Luciano et al., 2014; Van Schalkwyk et al., 2015) also indicated that mental health professionals' failure to collect information about developmental history, and lack of understanding about ASC presentation, contributed to mental health misdiagnoses in both individuals with an existing autism diagnosis and those who obtained a diagnosis during the studies. Misdiagnosis of ASC as a mental health condition could lead to unnecessary treatment (e.g. medication), which could preclude the possibility of having other, more relevant, needs met.

While previous case studies (Dosseter, 2007; Luciano et al., 2014; Van Schalkwyk et al., 2015) provide important clues to the contributing factors for mental health misdiagnosis in autistic individuals from the perspective of professionals specialising in ASC, there is currently little known about autistic individuals' subjective experience of mental health diagnosis and perceived misdiagnosis. Therefore, this article aims to address the following research questions: (1) Are autistic individuals more likely to report receiving mental health diagnosis(es) and if so, what kind of diagnoses were they more likely to receive? (2) Are autistic individuals more likely to disagree with these diagnoses? and (3) What were the reasons behind any disagreement?

Three participant groups were included, comprising individuals who were identified as autistic, non-autistic or possibly autistic. Inclusion of the non-autistic group allowed us to examine whether mental health diagnoses

and perceived misdiagnoses were more common in autistic individuals compared to the general population. We included a group of possibly autistic people who reported suspecting that they may have an undiagnosed ASC. The reasons for this are that yet-to-be-diagnosed autistic individuals may be particularly vulnerable to misdiagnosis of mental health conditions (Dosseter, 2007; Luciano et al., 2014; Van Schalkwyk et al., 2015) and also that autistic individuals often play an important role in the recognition of their ASC. Jones et al. (2014) looked at the experience of those who had received an ASC diagnosis and found that 44.5% of their respondents reported raising the possibility of ASC themselves, whereas only 4.1% reported that a professional raised the possibility. It is also well known that certain characteristics affect the likelihood of receiving an autism diagnosis, for example, females are diagnosed less frequently than males (Brugha et al., 2011). This may be due to differences in presentation, such as better nonverbal communication skills and the ability to camouflage other diagnostic features (Rynkiewicz et al., 2016). Seeking a diagnosis in adulthood may be problematic due to the development of compensatory strategies and a possible lack of informant (e.g. parent) for developmental history (Lai and Baron-Cohen, 2015). For these reasons, it is important for the experiences of this previously under-researched group, namely, possibly autistic adults, to be heard.

## Method

### Materials

*Survey development.* Research priorities for the autism community can be very different from those of the researchers (Pellicano et al., 2014). Therefore, it is important that autistic people participate in setting priorities to ensure that the research conducted is useful to those most affected by it (Fletcher-Watson et al., 2018). As such, an online survey exploring various topics including mental health diagnoses, self-injury and suicidality was developed in partnership with a steering group of eight autistic adults (six females, two males) through a series of six focus groups (see Cassidy et al., 2018c, for details of the full data set). At the start of the study, the steering group discussed what their role should be and decided it would be to inform the study conception, design, recruitment and dissemination of results. The first three focus groups focused on developing the questions in the online survey about a number of topics identified from a systematic review of the literature thought to be important contributors to mental health and suicidality in autism. The focus group fed back on the relevance of these proposed topics, whether any important topics were missing and their own experiences in relation to the topics identified. The researchers then developed a survey with questions that

would allow participants' experiences of these topics to be captured. Once the survey had been designed, the steering group provided feedback on three drafts until agreement was reached that the questions were comprehensive, relevant and clear. The data collected in relation to mental health diagnoses were analysed and are reported in this article. Data relating to other topics collected from the survey are reported elsewhere (see Camm-Crosbie et al., 2018).

*Mental health diagnosis questions.* Participants answered closed- and open-ended questions on their mental health diagnoses. First, they were asked 'Have you ever been diagnosed with a mental health condition(s) or other condition(s) by a trained clinician?' to which they responded with either 'Yes' or 'No'. They were subsequently asked to select the specific mental health or other condition(s) including 'Depression, Anxiety, Obsessive Compulsive Disorder (OCD), Bipolar, Personality Disorder, Schizophrenia, Anorexia, Bulimia and Other'. If participants selected 'Personality Disorder' or 'Other' from the list, they were given a free text box to specify the subtype of Personality Disorder or other mental health conditions they were diagnosed with. Participants were then asked, 'Do you agree with your diagnosis/es', with the following response options: 'Yes', 'No' or 'Not entirely'. If participants selected 'No' or 'Not entirely', they were subsequently asked, 'Please tell us what mental health diagnosis/es you disagree with, and why' and indicated their response using a free text box.

These diagnoses and order were chosen due to a combination of standard questions our group regularly uses in previously published research and also feedback from the steering group regarding clarity. For example, participants noted that it was easier to have staged questions starting wide, and then narrowing (Personality Disorder subtype), to keep the survey questions relevant throughout.

*Demographic questions.* As part of the survey, participants were asked to provide information such as age, gender, autism diagnosis and age of diagnosis. Participants were divided into three groups for analysis based on their autism diagnostic status. Participants in the *non-autistic group* reported no formal diagnosis of ASC and no suspicion that they have ASC. Participants in the *autistic group* reported receiving a formal diagnosis of ASC from a qualified clinician. Participants in the *possibly autistic group* reported that they thought they may have ASC and either (1) were awaiting assessment from a qualified clinician or (2) had not yet sought an assessment.

*Autism Spectrum Quotient.* The Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001) is a measure of autistic traits with scores ranging from 0 to 50. Greater scores indicate higher levels of autistic traits. Participants rated themselves on 50 statements with the options 'Definitely Agree', 'Slightly Agree', 'Slightly Disagree' and 'Definitely Disagree'. Woodbury-Smith et al. (2005) recommended a cut-off of 26 for screening in clinical practice and a cut-off of 32 for the general population, to limit false positives. We followed Hoekstra et al.'s (2007) methodology to manage missing items. If five or fewer items were left blank, the following equation was used to correct for the number of missing items: total subscale score + (mean subscale item score × number of missing items in subscale). The corrected subscale scores were summed to get the total AQ score. Missing items accounted for 0.19% of the analysed data. If a participant left more than five items blank, their data were discarded. Two participants' data were excluded based on this criterion.

## Participants

Participants were recruited through charities, Cambridge Autism Research Database (CARD), Cambridge Psychology, online advertisement, MHAutism newsletter and MHAutism webpage (http://mhautism.coventry.ac.uk). Participants were invited to take part in an online survey exploring experiences of mental health problems, self-injury and suicidality and could take part regardless of prior experience of these difficulties. Data from 420 adults (18–67 years) who completed the 'mental health diagnoses' section of the online survey were analysed. Data from respondents who did not report their age ($n = 52$), gender ($n = 3$) or diagnostic status ($n = 0$) were excluded. The autistic group was significantly younger than the non-autistic group ($p = 0.013$), and there was a significantly greater proportion of males and smaller proportion of females compared to both the possible autistic and non-autistic groups ($ps > 0.05$). Welch's analysis of variance (ANOVA) revealed that there were significant between-group differences in AQ scores, $F(2, 189) = 281, p < 0.001$. Autistic and possibly autistic participants scored significantly higher on the AQ than non-autistic participants ($ps < 0.001$). Autistic participants also scored significantly higher than possibly autistic participants on the AQ ($p = 0.005$). Participants' characteristics are reported in Table 1.

## Procedure

The study was approved by Coventry University Psychology Ethics Committee, the autism steering group who fed back on the questionnaire and the scientific advisory group at the Autism Research Centre, University of Cambridge. Participants were invited to complete the survey on Qualtrics (https://www.qualtrics.com/uk/). Participants read the participant information sheet and indicated informed consent to participate via an online form. Participants were fully briefed about the nature of

**Table 1.** Participants' characteristics.

|  | Autistic (n = 208) | Possibly autistic (n = 71) | Non-autistic (n = 141) |
|---|---|---|---|
| Mean age (SD), range | 38.6 (11.4), 18–67 | 40.1 (8.9), 20–57 | 42.1 (10.6), 20–60 |
| Number of males | 72 (34.6%) | 11 (15.5%) | 20 (14.2%) |
| Number of females | 136 (65.4%) | 60 (84.5%) | 121 (85.8%) |
| Mean AQ (SD) | 38.6 (6.8) | 35.8 (5.9) | 17.5 (8.7) |
| Mean age of diagnosis (SD), range | 34.5 (12.2), 4–59 |  |  |

SD: standard deviation.

**Table 2.** Number of participants who reported diagnosis of mental health condition or other conditions.

| 'Have you ever been diagnosed with a mental health condition(s) or other condition(s) by a trained clinician?' | Autistic (n = 208) | Possibly autistic (n = 71) | Non-autistic (n = 141) |
|---|---|---|---|
| Yes | 183 (88%) | 57 (80.3%) | 74 (52.5%) |
| No | 25 (12.0%) | 14 (19.7%) | 67 (47.5%) |

the research, that they could skip sections and/or questions that they felt uncomfortable with, and were provided with information about relevant support services before and after participation.

### Analysis

*Quantitative analysis.* Statistical analyses were conducted using SPSS version 24. Chi-square tests for homogeneity were computed to test for between-group differences in the proportions of (1) individuals reported receiving mental health and other diagnoses, (2) specific mental health diagnoses received and (3) agreement with mental health diagnoses. If a chi-square was significant, post-hoc $z$ tests were then computed to further examine pairwise differences in group proportions with automated adjusted $p$-values (Bonferroni method). Fisher's exact tests were used instead if any of the expected cell count were less than 5. Cramer's $V$ was calculated for effect size (small effect = 0.1, medium effect = 0.3, large effect = 0.5; Cohen, 1988).

*Qualitative analysis.* Thematic analysis was conducted for participants' responses to the question, 'Please tell us what mental health diagnosis/es you disagree with, and why'. Responses with no mention of the specific diagnosis(es) they disagreed with were excluded. Braun and Clarke's (2006) methodology for thematic analysis was followed. This enabled exploration of the research question in a data-driven manner informed by participants' perspective and experience. S.K.A-Y. read through the responses to gain an overall impression of the data set and noted any emerging patterns. The responses were then reread and initial codes were generated. Codes describing similar concepts were grouped into preliminary themes and subthemes, which were subsequently reviewed by A.E.R., L.B. and S.C. Discussion among the authors led to further refinement of the themes. Thereafter, related themes and subthemes were consolidated, while those that were deemed to not meaningfully address the research question were discarded.

### Results

#### Rate of lifetime mental health diagnoses and other conditions

There were significant between-group differences in the proportions of participants reporting mental health or other diagnoses, $\chi^2(2) = 57.5$, $p < 0.001$, $V = 0.370$ (see Table 2). Autistic and possibly autistic participants were more likely to report receiving mental health or other diagnoses compared to non-autistic participants ($p < 0.05$). There was no significant difference between autistic and possibly autistic participants ($p < 0.05$).

Thereafter, we compared the proportion of individuals reporting specific mental health diagnosis between groups (see Table 3 for omnibus test statistics and pairwise comparisons). Types of diagnoses that participants selected or mentioned were grouped for analysis based on *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5 classifications; APA, 2013). There were no significant between-group differences in proportion of individuals who reported diagnosis of Schizophrenia and Other Psychotic Disorders, Bipolar and Related Disorders, Dissociative Disorders, Gender Dysphoria and Substance Related and Addictive Disorders. However, there were significant between-group differences in the proportion of individuals reporting diagnoses of Depressive Disorders, Anxiety Disorders, Obsessive Compulsive and Related Disorders, Trauma and Stressor Related Disorder, Feeding and Eating Disorders and Personality Disorders, with consistently greater number of participants in the autistic and/or possibly autistic groups reporting these diagnoses.

**Table 3.** Number of participants who reported mental health diagnoses.

| | Autistic (n = 208) | | Possibly autistic (n = 71) | | Non-autistic (n = 141) | | Omnibus test | Pairwise comparisons |
|---|---|---|---|---|---|---|---|---|
| Depressive Disorders | 161 | (77.4%) | 52 | (73.2%) | 60 | (42.6%) | $\chi^2(2) = 47.4, p < 0.001$, $V = 0.336$ | ASC > NASC PASC > NASC ASC = PASC |
| Anxiety Disorders | 148 | (71.2%) | 45 | (63.4%) | 48 | (34%) | $\chi^2(2) = 48.6\ p < 0.001$, $V = 0.340$ | ASC > NASC PASC > NASC ASC = PASC |
| Obsessive-Compulsive and Related Disorders | 40 | (19.2%) | 8 | (11.3%) | 3 | (2.1%) | $\chi^2(2) = 23.1, p < 0.001$, $V = 0.235$ | ASC > NASC PASC > NASC ASC = PASC |
| Personality Disorders | 25 | (12.0%) | 8 | (11.3%) | 6 | (4.3%) | $\chi^2(2) = 6.41, p = 0.041$, $V = 0.124$ | ASC > NASC ASC = PASC PASC = NASC |
| Feeding and Eating Disorders | 21 | (10.1%) | 8 | (11.3%) | 4 | (2.8%) | $\chi^2(2) = 7.49, p = 0.024$, $V = 0.134$ | ASC > NASC PASC > NASC ASC = PASC |
| Bipolar and Related Disorders | 12 | (5.8%) | 5 | (7%) | 2 | (1.4%) | Fisher's exact test = 5.49, $p = 0.051, V = 0.108$ | |
| Schizophrenia Spectrum and Other Psychotic Disorders | 7 | (3.4%) | 3 | (4.2%) | 1 | (0.7%) | Fisher's exact test = 3.49, $p = 0.149, V = 0.087$ | |
| Trauma and Stressor Related Disorders | 6 | (2.9%) | 6 | (8.5%) | 1 | (0.7%) | Fisher's exact test = 8.19, $p = 0.012, V = 0.150$ | PASC > NASC ASC = NASC ASC = PASC |
| Gender Dysphoria | 2 | (1%) | 0 | (0%) | 1 | (0.7%) | Fisher's exact test = 0.505, $p = 1.00, V = 0.041$ | |
| Dissociative Disorders | 0 | (0%) | 1 | (1.4%) | 0 | (0%) | Fisher's exact test = 3.46, $p = 0.169, V = 0.108$ | |
| Substance Related and Addictive Disorders | 0 | (0%) | 1 | (1.4%) | 0 | (0%) | Fisher's exact test = 3.46, $p = 0.169, V = 0.108$ | |

ASC: autistic group; NASC = non-autistic group; PASC = possibly autistic group. More detailed analyses were carried out on the subtypes of personality disorders, but no significant between-group differences were found (see Supplemental Materials A).

**Table 4.** Number of participants who show agreement or disagreement with their mental health diagnosis.

| 'Do you agree with your mental health diagnosis/es?' | Autistic (n = 182) | Possibly autistic (n = 57) | Non-autistic (n = 74) |
|---|---|---|---|
| Yes | 106 (58.2%) | 26 (45.6%) | 64 (86.5%) |
| No | 12 (6.6%) | 2 (3.5%) | 3 (4.1%) |
| Not entirely | 64 (35.2%) | 29 (50.9%) | 7 (9.5%) |

### Disagreement with mental health diagnosis

There were significant between-group differences in the proportion of individuals who reported disagreement with their mental health diagnoses as denoted in response to an open-ended question on this topic, Fisher's exact test = 31.8, $p < 0.001$, $V = 0.218$ (see Table 4). Two of the post-hoc pairwise comparisons were significant: these were the 2 (non-autistic vs autistic) × 2 (Yes vs Not entirely) comparison and the 2 (non-autistic vs possibly autistic) × 2 (Yes vs Not entirely) comparison (both $ps < 0.001$). These showed that a higher proportion of autistic and possibly autistic participants did not entirely agree with their mental health diagnosis compared to non-autistic participants, while a greater proportion of non-autistic participants agreed with their mental health diagnosis compared to the other two groups. None of the other seven comparisons reached significance ($ps > 0.05$). Proportions of participants who disagreed with specific type of mental health diagnoses were compared between groups, but no significant differences were found (see Supplemental Materials B).

## *Thematic analysis*

This section explored the reasons underlying disagreement with mental health diagnosis(es). Data for the autistic and possibly autistic participants were analysed together, because our quantitative analysis showed that both groups were significantly more likely to report disagreement with their mental health diagnoses compared to the non-autistic group (see Table 4). Therefore, it is likely that participants in the possibly autistic group have shared experiences with those in the autistic group. Spelling and grammatical errors were corrected in participants' extracts; these are denoted in square brackets in the quotes. Each quote is followed by a participant number and their diagnostic status (ASC = autistic, PASC = possibly autistic). Data from the non-autistic group were not analysed as very few of these participants showed disagreement and responded to the open-ended question. Two major themes emerged from the thematic analysis: 'Problems with Mental Health Diagnosis' and 'Clinical Barriers'.

*Problems with mental health diagnosis*. This theme consists of two sub-themes: 'ASC characteristics confused with symptoms of a mental health condition' and 'mental health difficulties perceived to be resultant of ASC'.

*ASC characteristics confused with symptoms of a mental health condition*. The first most common reason for participants' disagreement with their mental health diagnoses was that they felt their ASC characteristics were mistaken as symptoms of a mental health condition. For example, in the following extract, an autistic participant explains how their difficulties with emotional regulation and self-injurious behaviours may have been misinterpreted as symptoms of a borderline personality disorder (BPD):[2]

> … [it's] just aspergers with me, the out coming behaviour might look or even be the same sometimes ([self-harm], getting [emotional] etc) but the causes are completely different- [I] learnt to hide my emotions and feelings to survive school and home without being hurt so only [got] visibly upset in the last moment when [it became] unbearable- just because they cannot read my face [doesn't] mean [I'm] not having those emotions before … (153-ASC)

The same participant also reported that their lack of eye contact was mistaken as evidence of schizophrenia rather than social communication difficulty in ASC:

> … I was given anti-psychotics for my behaviour … they think because [I don't] look at them and [I] am nervous of talking then [I] am 'guarded' or have 'flat affect' … (153-ASC)

One possibly autistic participant did not 'entirely agree' with their Trauma and Stressor Related Disorder diagnosis because they felt their difficulties with resistance to change could be better explained by ASC, and specifically, the category of 'restricted, repetitive patterns of behaviour, interests, or activities' (APA, 2013):

> … I think that ties in with possibly having an ASC as not coping well with change is a characteristic of that. (445-PASC)

Similarly, another possibly autistic participant who received a bipolar disorder diagnosis felt their intense interest had been mistaken as a sign of mania:

> … I get mood swings, but I believe that is more due to the Autism than manic depression. I am subdued when I am uncomfortable and what may look manic when I am doing something I like … (238-PASC)

Some participants spoke about sensory sensitivities that they felt were mistaken as eating disorders or psychotic symptoms:

> My issues with food were regarding the texture and the act of eating. (452-PASC)

> I stopped going to the school canteen as a teenager and lost a lot of weight because I couldn't stand the social/sensory environment. (2-ASC)

> I am also not psychotic – I have [enhanced] sensory perception. (28-ASC)

In addition to having autism characteristics miscategorised by healthcare professionals, some participants thought clues that were indicative of ASC might have been missed. One autistic participant diagnosed with personality disorder reported:

> … autism runs so strongly in my family (all four children have AS/autism, and I think my father probably has Asperger Syndrome). (175-ASC)

Likewise, a possibly autistic participant who was diagnosed with OCD reported,

> … I suspect that is really ASC, but it was the 80s and I am female. I have never been able to deal with much of anything in the morning, and apparently shoe tying before school was the last straw when little. (741-PASC)

These extracts highlight that the importance of family history and behavioural patterns in early childhood in making differential diagnosis between mental health conditions and ASC.

*Mental health difficulties perceived to be resultant of ASC*. The second most common reason for participants' disagreement with their mental health diagnoses was because they felt that their mental health conditions were resultant of the difficulties they experienced as part of

living with ASC. These feelings were especially prevalent in participants who received depression and anxiety diagnoses (nine participants). One autistic participant explained that their depression stemmed from difficulties connecting with others:

> … because I did not ever really fit in socially and I couldn't understand what I was doing wrong, why people made friends but didn't include me, why I could never work out when to join in a conversation in a group situation etc, I was depressed because I thought I must be a very bad [unlovable] person. Now I know I definitely have Aspergers I understand why I don't often connect with others properly. (120-ASC)

Another autistic participant reported that their depression and anxiety were a result of difficulties dealing with social demands:

> Depression and anxiety were a reaction to stress associated with having autistic spectrum difficulties. I am not anxious and depressed when I am in a **suitable** environment [emphasis added]. (468-ASC)

Daily living can be exhausting for autistic individuals, which could manifest as symptoms of depression. This was experienced by the following participant who disagreed with her depression diagnosis:

> … I live in a society that is not a suitable environment in which I can thrive, as I am autistic. It is hard to access accommodations. People are not kind and ask ignorant and hurtful questions, and make harmful assumptions when I plead with them to be accommodating as I am autistic. This is quite taxing, and I often feel very tired. (480-ASC)

An autistic participant felt that due to their autism not being understood, healthcare professionals tended to focus on the co-occurring mental health condition – a more useful treatment would be to address their psycho-social needs:

> … My underlying ASC is hard to explain [to] the GP in that I have expressed that I feel my depression is only a result of my, kind of, 'untreated Autism' in effect. Meaning, that if I can find help through relevant counselling, connecting with others, to accept and understand the autistic side of me and discover what my real needs are then I have a chance at learning a new vocabulary to express those needs and this will greatly reduce the resultant mental health issues that [recur], particularly depression. (178-ASC)

This kind of support, however, may be difficult to access – the second theme explores why this is the case.

*Clinical barriers.* This theme describes the clinical barriers participants faced in seeking accurate diagnosis and support. These barriers were related to the participants' interactions and experiences with healthcare professionals, who they felt either:

> … didn't understand me. (1-ASC)

Or lacked an understanding of ASC:

> … [the] health professionals who diagnosed BPD aren't familiar enough with the symptoms of a female with AS … Now it feels like I've got a BPD diagnosis and they refuse to look at anything else. (196-ASC)

Other participants felt some healthcare professionals did not communicate with them. The following participants reported not having appropriate discussions regarding their diagnoses, and not being listened to, or given opportunities to raise concerns:

> I never had a proper assessment or discussion for my diagnosis of EUPD[2] and nobody told me, it just appeared on my medical records. (586-PASC)

> … I was misdiagnosed but no one would listen to me and I was told I was lying when I tried to explain. (2-ASC)

> … After obtaining medical notes, it is clear that my account of my experiences were being misunderstood and I was not given opportunities to clarify as information was withheld from me … (8-ASC)

The consequence of a lack of autism awareness and communication was that it hindered participants receiving adequate support and having their needs met. The following autistic participants reported dissatisfaction with medication being the focus of their treatment:

> … I feel my GP is focusing purely on the depression and once he has a 'result' through the anti-depressants, then I will be deemed fully well again. Although I have taken the anti-depressants for 8 weeks now, I still struggle with dark thoughts, feelings of wanting to end it all and find life poses the same difficulties to me when it comes to functioning. (178-ASC)

> … my GP tries to keep throwing antidepressants at me but [I] think [I] just need to understand myself better [and] get other conditions diagnosed. (468-ASC)

Similarly, a possibly autistic participant talked about comparable experience with regard to therapeutic interventions received, with the focus on the treating the mental health condition overshadowing their undiagnosed autism:

> … I've had therapy with MIND[3] and [counselling] sessions, although they helped at the time, no one got to the bottom of what was wrong. (24-PASC)

The following participant's experience is a fitting illustration of this theme and the difficulties participants face in seeking accurate diagnosis and support. This participant was misdiagnosed with bipolar and prescribed various

medications over many years to manage a condition they did not have:

> … I had a formal diagnosis of bipolar (II) condition for around 17 years. I actually satisfy the DSM criteria for this, but have only [ever] been hypomanic once and that was antidepressant induced. I don't benefit from mood stabilisers, antipsychotics or most antidepressants, and things like stress, working long days and staying up late don't induce mania. I have tried lots of different medications over the years, but for most of my [years] with a bipolar diagnosis, I worked in developing countries, didn't take any [psychotropic medications] and remained relatively mentally well … Hence, once my autism had been diagnosed, I was able to get a consultant psychiatrist to say that she didn't think I'd ever had bipolar and it has been revoked as a current diagnosis. (339-ASC)

## Discussion

This study explored the experience of mental health diagnosis comparing non-autistic, autistic and possibly autistic people and addressed the following research questions: (1) Are autistic individuals more likely to report receiving mental health diagnosis(es) and if so, what kind of diagnoses are they more likely to receive? (2) Are autistic individuals more likely to disagree with these diagnoses? (3) What were the reasons behind any disagreement? We found that autistic and possibly autistic adults reported receiving more mental health diagnoses compared to non-autistic adults. Specifically, significant differences were found for Depressive Disorders, Anxiety Disorders, Obsessive Compulsive and Related Disorders, Trauma and Stress Related Disorders, Feeding and Eating Disorders and Personality Disorders. Autistic and possibly autistic adults were also significantly less likely to agree with their mental health diagnoses than non-autistic adults. There were two major reasons for their disagreement: (1) ASC characteristics were confused with symptoms of a mental health condition and (2) mental health difficulties perceived to be resultant of ASC. Autistic and possibly autistic individuals spoke about the clinical barriers that hinder accurate diagnosis and support, which include healthcare professionals' lack of awareness and understanding of autism, poor communication between autistic adults and healthcare professionals and treatment not being suited to their needs.

Our findings are consistent with previous research documenting that autistic people (both diagnosed and undiagnosed) experience greater rates of co-occurring mental health conditions compared to the general population (Lever and Geurts, 2016). There may be several reasons as to why autistic people are more vulnerable to developing mental health conditions. For example, Haruvi-Lamdan et al. (2017) suggested that autistic people are more likely to experience stressful or traumatic life events such as being bullied or ostracised; cognitive features (e.g. having

rigid thinking and rumination) may also affect how stressful events are processed; additionally, sensory sensitivities and sudden changes in routines and environment are a source of stress for autistic individuals over and above what is experienced by non-autistic individuals. Although the effect of these factors on autistic people's mental health is not yet fully understood, it seems clear that these are significant and widespread issues within the autistic population.

Our findings showed that only half of the participants in both the autistic (58.2%) and possibly autistic (45.5%) groups agreed with the mental health diagnosis(es) they received, compared to over 86.5% in the non-autistic group. Qualitative responses from autistic and possibly autistic participants indicated that similarities in symptom presentation between ASC and a range of mental health conditions could be the source of these perceived misdiagnoses. Crane et al. (2018) conducted a survey and interviews exploring the mental health experience of young autistic people (16–25 years). They found that young autistic people perceive themselves as different from non-autistic people in many domains (e.g. that they are more likely to feel under strain or unhappy) even when they are not experiencing a mental health problem. This has implications for the development of diagnostic tools, because it could be the case that measures developed with the general population in mind may therefore fail to tease apart whether an autistic person is experiencing psychological distress that is over and above their typical behavioural presentation. One of the current research priorities of our group is to develop validated diagnostic tools to accurately assess mental health conditions in the autistic population (Cassidy et al., 2018a, 2018b).

Another contributing factor to the participants' perceived misdiagnosis was the lack of awareness and understanding of ASC among healthcare professionals. This study highlights the importance of autism awareness training for health and social care professionals, as outlined by statutory guidance (Department of Health, March 2015). Such training would arm professionals with the confidence to communicate with, understand and support autistic people. Mental health professionals should be trained to understand the cognitive differences between autistic and neurotypical people, which will help them modify therapeutic interventions so they are effective for autistic people. In addition, more research is needed to test the effectiveness of modified therapeutic interventions and medications for various mental health conditions for the autistic population.

An important topic arose from our qualitative analysis relating to diagnostic overshadowing. Our participants reported that they felt healthcare professionals gave priority to treating mental health conditions and thus leaving the underlying autism unaddressed and other psychosocial needs unmet. Similarly, in the study by Crane et al.

(2018), interviews with young autistic people highlighted numerous barriers for support. These included services not being tailored to their needs in relation to their autism, diagnostic and mental health services being 'disjointed', and worse, available support becoming even scarcer when they transitioned to adulthood. Given that many autistic adults received their diagnosis in adulthood, there is a real need to develop adequate post-diagnostic support systems. Post-diagnostic support could include: psycho-social education; provision of opportunities for autistic people to connect with others through local support networks; advocacy services to support autistic people to express their needs; and signposting to local resources. Mainstream services such as adult mental health services may also benefit from the support and consultation of a specialised ASC service in the local area (see National Institute for Health and Care Excellence (NICE), 2014, for the Bristol Model).

## Strengths and limitations

A key strength and novel aspect of this study was the participatory approach, where autistic adults prioritised the study topic and questions utilised in the research. This ensured that the study was relevant, important and clear to autistic people and thus more likely to be useful to their daily lives – a feature lacking in much previous autism research (Fletcher-Watson et al., 2018; Pellicano et al., 2014). Furthermore, we included possibly autistic people in the study who had not yet been formerly diagnosed, but strongly identified as autistic, as suggested by our autistic steering group. This inclusion allowed us to explore whether yet-to-be-diagnosed autistic adults shared similar experiences with those with a clinically confirmed diagnosis of ASC, which was important given many autistic adults remained undiagnosed or received a diagnosis much later in life (Lai and Baron-Cohen, 2015). Interestingly, the results from the confirmed and possibly autistic groups were very similar. The mean AQ score of the possibly autistic group (35.8) was well above the recommended cut-off (32+) for clinically significant level of autistic traits, and similar rates of mental health diagnoses and level of disagreement indicated shared experiences between these groups. However, we do acknowledge that there is no way of knowing whether participants in the possibly autistic group truly met the diagnostic criteria of ASC without a comprehensive clinical assessment.

We found lifetime rate of mental health and other diagnoses to be 88% for the autistic group and 52.5% for the non-autistic group. Previous work by Lever and Geurts (2016) reported similar lifetime rates of psychiatric conditions in their autistic sample (79%) and non-autistic group (48.8%). This shows that that the self-reported rates of mental health diagnoses in our study are consistent with previously reported rates using standardised instruments for diagnosing mental health disorders. However, we are unable to verify whether the self-reported rates of disagreement consistent with actual rate of misdiagnosis due to the lack of previous research in this area. We are also unable to conclude whether autistic and possibly autistic individuals were more likely to disagree with *specific* mental health diagnoses that they received because of the small sample size for the disagreement data; therefore, these comparisons are likely to lack power and should be interpreted with caution (see Supplemental Materials B).

Finally, the self-selecting nature of our sample meant that it was not possible for us to control the variability in age and gender. How might these confounding variables have influenced our findings? First, we might expect that participant groups with higher age to have a higher rate of lifetime mental health diagnosis, however, this was not the case; our autistic group reported significantly more lifetime mental health diagnoses despite being statistically younger than the non-autistic group. Second, we might expect that the participant group with greater proportion of females to have higher rates of lifetime mental health diagnosis based on findings previously reported for females, in particular, for mood and anxiety disorders (Riecher-Rössler, 2016). This is again not the case in our sample; our autistic group reported significantly higher rates of mental health diagnosis despite having a smaller proportion of females. While these confounding variables do not seem to have affected the findings in the predicted manner, we acknowledge that the confounding variables still pose a limitation to the study and may affect the generalisability of our findings.

## Notes

1. We use the term condition, rather than disorder, in recognition of the strengths and difficulties associated with autism and in order to be less stigmatising. Recent research has also found that the autistic community uses a range of terms to describe autism, but the term 'autistic person' is most preferred (Kenny et al., 2016). Thus, we use the terms ASC, autism and autistic synonymously throughout this article in recognition of this.
2. The abbreviated terms for Borderline Personality Disorder (BPD) and Emotionally Unstable Personality Disorder (EUPD) were used interchangeably in participants' extract; these are synonyms for the same condition.
3. Mind is a registered mental health charity and company that provides advice and support to anyone experiencing a mental health problem across England and Wales.

## Supplemental material

Supplemental material for this article is available online.

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